

ETHICS OF RESEARCH PUBLISHING

Action v inaction: a case history in ethics

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The motives behind the author's decision to resuscitate a patient are examined. This is prompted by the realisation that he ignored the man's apparent wish not to be saved for fear of criticism from both relatives and colleagues. The way in which decisions are made when the interests of the doctor and the patient clash are briefly explored. Self interest may play a more significant role than is commonly accepted.

At three o'clock in the morning I was called to see a patient in respiratory distress. Arriving at the door of the side room I saw a thin, immobile man on the verge of respiratory arrest. His body was misshapen, his legs flexed and wasted, his chest protuberant and barrel shaped. There was an electric wheelchair in the corner of the room. The house officer, who had been struggling with him for 10 minutes, looked up.

"Spinal muscular atrophy. He's being treated for pneumonia, query aspiration."

I lowered the back of the bed and with a bag and mask assisted his ventilation. A small bolus of adrenaline strengthened what had been a barely palpable pulse. He soon began to breathe more frequently and more deeply. He mumbled for the first time, and his eyes appeared to focus on those who were standing by his bed.

"He's probably good enough for some non-invasive ventilation..." I said, "we might get away without intubating him. Can you carry on doing this for a minute, just squeezing the bag when he breathes... gently, I'm going to have a quick chat with his relatives."

The relatives, his brother and sister, were waiting by the door. They had observed everything. I introduced myself, confirmed with them the nature of their brother's neurological condition and continued:

"The infection has progressed despite the antibiotics, and that, combined with his long standing weakness, has restricted his breathing. The carbon dioxide has built up inside him and made him drowsy. He's a little better already, but he needs more help with his breathing."

"Whatever it takes doctor. Just get him better."

"We will try, but I can't overemphasise how unwell he is. He may need to go on a ventilator." They nodded, and gazed past me into the room. The nurse touched my arm and pointed to the door. I entered to see the patient looking pinker and stronger. He was grasping the house officer's hand, trying to push him away. The medical notes lay open on the bedside cabinet, where the house officer could read them.

"He's got cancer. Gastric cancer."

"What?"

"It says here... these notes are so crap, it says he's recently had chemo." I turned on my heels and left the room again.

"Excuse me. The notes indicate that your brother has been receiving treatment for stomach cancer."

"Yes, he has."

"When was this?"

"A few weeks ago. They said it was successful."

"Has he had an operation?"

"No."

"Is he due to have one?"

"I don't think so. They're just treating it with injections."

"I'm sorry to be blunt... but this is very important... has he been told, or has he told you, that his cancer is incurable or terminal?"

"No. No doctor."

I paused, concerned that in the haste demanded by this situation I appeared to be writing the patient off.

"Has he ever talked to you about what he would want if he fell seriously ill and needed intensive care, or a life support machine?"

"No."

"He's never expressed an opinion about it?"

"About what?"

"About being kept alive on a ventilator."

"No, never."

The nurse stayed with the relatives. I joined the house officer in the side room and with a mobile internal phone arranged a bed on the respiratory ward. The patient was sitting up again now, still terribly distressed, but looking around. We arrived on the ward to find a non-invasive ventilator set up in readiness. I placed the mask over his nose and mouth. He grabbed my wrist, but I resisted the force and pressed hard to ensure an airtight seal. He cringed beneath the pressure of the plastic, and shook his head again and again. The exaggerated bone structure of his emaciated face conveyed desperation and fear. It was impossible to fix the elastic straps behind his head. The relatives had followed us to the ward. His sister held his left hand.

"Let them put it on. You need it for your breathing. Let them do it. It won't be for long, will it doctor?"

"No, not for long."

"You see, it's just to get you over the infection."

I tried again. He held his sister with his gaze for a few seconds, and then closed his eyes in submission. His head fell back onto the pillow, he became still, and the mask was at last secured.

"What now doctor?"

"We'll have to see if this machine can do enough for him. If not he will need to go on a ventilator."

"Cancer. And not resected. There's something not right there," replied the intensive care

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registrar when I called to warn him of the possible transfer.

"But the family tell me it's been treated successfully. I've got no other information. They are pushing for full active treatment. We're going to have to offer everything until we get the full story in the cold light of day. Even if we knew who his oncologist was we could hardly call him at four in the morning."

An hour and a half later I called an anaesthetist. Mask ventilation had been unsuccessful. I watched as the patient was sedated, paralysed, and intubated.

At midday I passed through intensive care and asked the registrar how the patient was doing.

"We called his oncologist once the old notes had been retrieved from records . . . and he couldn't believe he'd been admitted to ICU. He's got inoperable, terminal cancer, a couple of months at most. We're pulling out once the relatives have had a chance to take it in. They're clueless."

"I see. Sorry about all that."

"Don't be . . . what can you do if the notes are incomplete? It's an impossible situation."

It appears that I had little choice but to treat him aggressively. I have, however, omitted something, one brief interaction. It took place just after my conversation with the brother and sister concerning the patient's cancer. The nurse and the relatives were outside, leaving just the house officer and myself in the side room. In response to the fear that I had detected in the patient's eyes I eased the rubber mask from his face and levelled my head in front of his.

"Do you want us to do this? Do you want us to help you?" I asked.

He could barely control his movements, but his eyes, ever articulate, spoke volumes. And in addition I detected, as I think did the house officer, a slow, controlled shake of the head. His answer was definitely No.

DISCUSSION

This was a disastrous situation. The last 48 hours of a terminally ill man's life were transformed into a demonstration of medicine's resuscitative prowess: ventilators, central lines, inotropes, discomfort combined with powerlessness . . . the last being a price worth paying if the underlying disease process is reversible, and the life regained worth living. Not so in this case. So why did it happen?

Information

Although the untidy outcome can be attributed to a degree of moral cowardice, discussed below, it would not have developed were it not for the inefficient transfer of information. The team that admitted this patient had no idea of the severity of his disease. In the absence of his old notes, their only source of information was the family, and they seemed genuinely to believe that his cancer had been treated "successfully". Either he had misunderstood the words of his oncologist, or perhaps, and this is most likely, the patient had given them a sanitised version. The notes being incomplete (comprising only the casualty card and two sheets of A4 on which the findings and decisions made during two ward rounds had been made) there was no clue as to the extent of the patient's knowledge, nor an indication of his wishes should he become unwell.

The decision

Why did I ignore the patient's wish to be left to die? In essence, I decided that action would be easier to defend than inaction, even if, in my view, positive action was not in the patient's best

interests. The factors that swayed this decision were the relatives' obvious desire that their "successfully" treated brother "get better", and the reflex that is trained into doctors to *do something* when presented with a patient on the verge of death. Wilting against these powerful forces for action stood my *perception* that the patient did not want to be "saved". He could not talk. He could only look at me in an accusatory manner and shake his head. I might easily (and reasonably, to my peers) have dismissed the patient as not competent to make such a decision, given his shocked state. But he was competent, and his opinion was clear. Nevertheless, I could not bring myself to stand before the relatives and say: "He does not want to be put through all this."

"How do you know? Has he told you?" they would reply.

"Not exactly, but I'm sure it's what he wants. I can see it his eyes."

"How will I look?"

The above scenario, which concerns the question of life sustaining treatment in the context of uncertainty is one that is commonly met on the wards, especially out of hours, when the doctors on call are summoned to patients about whom they have no knowledge. The element in this particular case which drives us to dissect the motives behind the decisions we make is the shake of the head. Subjective, brief, easily erased by a mind craving simplicity and comfort . . . it immediately juxtaposed what the patient *wanted* with what I knew I *had* to do.

What my reaction to this mute signal tells us is that however strong our conviction that treatment is not in a patient's best interests, we will compromise in the face of pressure from relatives, or in a situation where death is likely to result from our lack of action. If there is the slightest doubt we treat, for that is what doctors do, and we are unlikely to be criticised for it. It is this fear of criticism, be it professional, legal, or merely vociferous, that is thus revealed as a prime motivator when difficult decisions are contemplated.

Clinical decisions are therefore seen to be modulated by professional and legal paranoia. They are scrutinised in the light of the question: "How will this make me look?" Usually the doctor's best interests coincide with the patient's, but this is not always so, and was probably not so in the case described here. The decision to treat this patient was based on *my* concerns about *my* situation. It would have taken an exceptionally brave, slightly naïve doctor to have acted otherwise.

Next time?

If put into the same situation again I would be more responsive to my instincts, delving more deeply into the "injections", and why the cancer had not been cut out. I would be less accepting of the contradictions, persisting in my attempts to find my way to the truth of the patient's terminal condition, which, for all I know, the family members were merely denying. And I might try harder to get the patient talking, so that I could act according to his explicit wishes, and not according to my fears. Nevertheless, all being equal, I would proceed with the immediately life saving measures. However humane the alternative, it has to be remembered that the patient, having died comfortably and without my meddling, would never have been able to back me up before the disgruntled relatives, or the concerned hospital management who would have dealt with the accusation of neglect. Fear of criticism would, once again, outweigh my instincts.